

Preface

The Advisory Commission on Services and Supports to Persons with Developmental Disabilities who do not have Mental Retardation – The Advisory Commission – is pleased to present to DMR Commissioner Peter O’Meara its final report. The Advisory Commission has committed over 19 months of study and deliberation in arriving at the conclusions represented in this document.

The Advisory Commission wishes to acknowledge the significant contributions of a number of people who provided substantial leadership, guidance, and behind-the-scenes work to promote the activities and efforts of the commission. Our sincere gratitude is extended to:

Dr. Barbara Intriligator of the **University of Hartford**, School of Educational Leadership. Dr. Intriligator has provided outstanding and consistent consultation to the Advisory Commission and its leadership. The value of expert and independent guidance, advice, and direct assistance cannot be overstated and has, we believe, greatly contributed to the quality of the Commission’s work.

The Council on Developmental Disabilities, and particularly **Mr. Ed Preneta** from the Council has provided substantial financial support and organizational leadership that has proved invaluable in promoting the work of the Commission. **Ms. Barbara Pankosky** from the Department of Mental Retardation has consistently worked behind the scenes and assumed important support and facilitation roles during Commission meetings.

Finally, we are pleased to acknowledge the hard work and outstanding leadership of **Dr. Diana LaRocco** from the Department of Mental Retardation. As project manager for this important initiative, Dr. LaRocco has made the most significant contribution through her thoughtful analyses, organizational leadership, substantial knowledge of issues associated with disabilities, direction and management of work group activities, and her consistent involvement in virtually all aspects of the Commission’s work.

We are hopeful that the findings and recommendations contained in this report can serve as a basis for a broader dialogue among public policy leaders in Connecticut. We believe that our findings and recommendations represent an accurate picture of what currently exists and more importantly of what needs to be done for persons with developmental disabilities. We also recognize that the introduction of change – “a new order of things” – is difficult and wrought with uncertainties. Nevertheless, such change must occur if Connecticut’s citizens with developmental disabilities are to enjoy a decent quality of life and are to be afforded the same rights and opportunities as all other citizens of our great state.

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I. The Commission

P.A. 00-135 Section 19(a)

established the Advisory Commission on Services and Supports for Persons with Developmental Disabilities (the Commission) in response to strong advocacy and growing concerns about limited support for individuals with developmental disabilities other than mental retardation. In establishing the Commission, the Connecticut General Assembly took a major step toward recognizing that the current landscape of state-sponsored services for many individuals with a developmental disability is inadequate to meet their needs for support and assistance.

Commission members represent a broad cross section of Connecticut and include individuals working with and advocating for individuals with developmental disabilities. A roster of Commission members is included in Appendix A of this report.

The Commission, which began meeting in November of 2000, was charged with providing a series of recommendations and advice in four major areas:

1. Define the population of people with a developmental disability;
2. Identify the types of services and supports they need,
3. Identify how such services and supports can be best delivered; and,
4. Identify the costs of providing these services and supports.

MAJOR QUESTIONS reviewed by the Commission

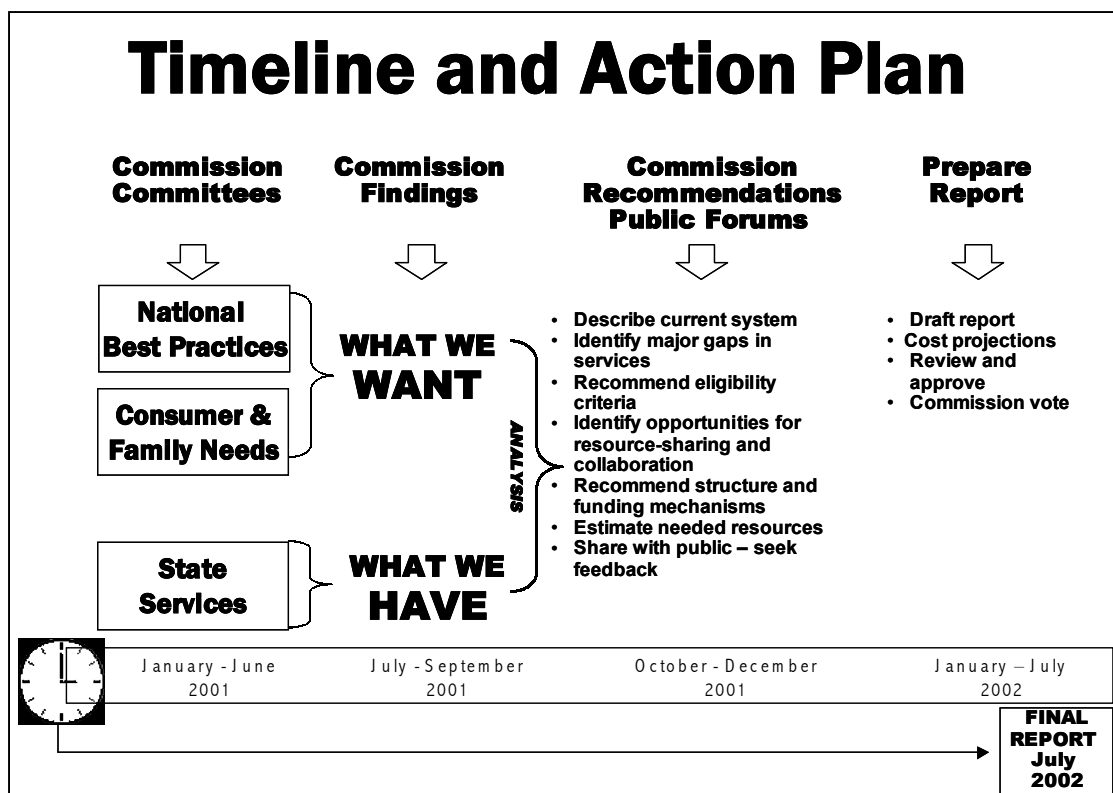
- 1. WHO needs to be served?**
- 2. HOW should Connecticut define eligibility?**
- 3. WHAT types of services are needed?**
- 4. WHICH state agency should oversee and fund these services?**
- 5. HOW should they be delivered?**
- 6. WHAT will it cost?**

The Commission established three (3) committees to carefully study issues associated with providing services to people with developmental disabilities and to form the basis for developing a set of recommendations. These work groups focused on:

1. National best practices and effective modes of service and support.
2. A thorough analysis of existing services provided by state agencies in Connecticut to identify patterns of use, gaps and duplication, and any unserved or under-served populations.

3. An assessment of self-identified consumer and family needs and preferences, barriers to receiving critical support, and recommendations for improvement to the Connecticut system.

The Commission then established a general plan for action that is illustrated below, and that included the need to present preliminary findings and recommendations no later than the 2002 Legislative session.



II. Developmental Disabilities

The concept of developmental disability (often referred to as DD) can sometimes be confusing to the average citizen, even though almost everyone personally knows or interacts with someone who has a developmental disability just about every day.

In a very general sense, a disability is a condition that requires an individual to sometimes need special assistance and support in order to lead a normal life and participate in all the natural activities of their community, consistent with their age and culture.

Developmental simply means that the disability occurred during the early developmental stages of life, usually considered anywhere from birth through entrance into adulthood (or around 18 to 21 years of age).

A developmental disability, therefore, is a condition that manifests itself before adulthood and may require some special supports. Depending upon the data source (e.g., Larson, Lakin, Anderson,

Kwak, Lee, & Anderson, 2000; The Developmental Disabilities Assistance and Bill of Rights Act, 2000) and the definition used, anywhere from ***1.2% and 1.65% of the U.S. population has a developmental disability.***

We can therefore project that ***in Connecticut there are between 40,867 to 56,192 citizens with a developmental disability.***

How Does the Definition of Mental Retardation Differ From Developmental Disability?

- Both mental retardation and developmental disability manifest before adulthood.
- Both mental retardation and developmental disability are defined by substantial limitations in adaptive behavior.
- To be classified as having mental retardation, however, a person **must** also show signs of a significant intellectual disability, with an IQ of usually less than 70 points.
- Most people with mental retardation have a developmental disability.
- Many people with a developmental disability do not have mental retardation.

There are wide ranges of conditions that can cause or are associated with developmental disabilities, including those listed in the table below. It is important to note, however, the specific criteria that are applied when defining developmental disabilities will greatly influence the expected prevalence. In other words, not all persons with the conditions listed in Table 1 would necessarily be considered to have a developmental disability.

Table 1. Estimated Prevalence of Select Conditions Associated with DD

Condition	No. per 1000
Mental Retardation	9.4
Cerebral Palsy	2.7
Spina Bifida	0.4
Autism	0.4
Autism Spectrum Disorders	2.6
Severe Hearing Impairment	1.2
Metabolic Disorders	0.3
Learning Disabilities	59.1
Seizure Disorders/Epilepsy	80.0
Acquired Brain Injury	2.6
Muscular Dystrophy	0.3
ADHD	43.3
Severe Visual Impairment	0.7

Developmental Disability Defined

The term developmental disability means a severe, chronic disability of an individual that-

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the individual attains age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - self-care,
 - receptive and expressive language,
 - learning,
 - mobility,
 - self-direction,
 - capacity for independent living,
 - economic self-sufficiency; and
- reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are lifelong or extended duration and are individually planned and coordinated.

An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described above if the individual, without services and supports, has a high probability of meeting those criteria later in life.